Exploring the impact of assistive technology for people with deafblindness in Southern Africa: a Delphi study

Meredith Prain summarises the findings from a study that she conducted with **Diane Bell** and **Natasha Layton**

Introduction

Assistive Technology (AT) is an umbrella term for assistive products and related services, the use of which maintains or improves a person's ability to function and be independent. AT is a key enabler of improved outcomes for people with disabilities, including those with deafblindness, in all life domains. However, tools are needed to assist people with disabilities to express needs, goals, and rights related to the use of AT, and to evaluate and measure AT-related outcomes, in order to make the case for appropriate AT provision.

Assistive products include devices, equipment, instruments, and software. AT services include assessment, product fitting, training, troubleshooting, and maintenance support, which are critical to the safe and effective use of products. AT is understood as a complex system requiring policies and markets that can deliver end to-end products and services. The application of systems thinking within the global AT community has identified five strategic drivers that are critical to realizing the full potential of AT for global citizens. Termed the '5 P's'and comprising people (that is, AT users and their socialUnetworks), policy, products, personnel, and provision, these form the basis of strategic actions by the World Health Organization (WHO) Global Access to AT (GATE) team. Additional, situational factors of procurement, place, pace, promotion, and partnership have been hypothesized as other critical factors influencing AT outcomes.

Deafblindness is a unique and isolating sensory disability, resulting from the combination of both hearing and vision loss or impairment that significantly affects communication, socialization, mobility, and daily living. Deafblind individuals use AT for the vision impaired, for example, long canes for mobility, screen, reading software, and refreshable braille displays and AT for deaf people, for example, hearing aids, and cochlear implants, as well as human supports, such as sign language interpreters and communication guides (support workers trained specifically to work one-to-one with people with deafblindness).

The Southern African Development Community (SADC) was selected as the focus of this study. Any research into AT and its impacts must be sensitive to context, and the impact of context upon capability. Reasons for selecting the SADC region included the emergence of an active Pan-African AT Community; evidence of strategic thinking about AT systems within the region, and the first Deafblind International Conference planned for Africa in 2022.

International calls for the sector-wide collection of AT outcomes data have been made for over two decades yet data is still not routinely collected, and consensus has not been reached on priority dimensions to be measured. However, work over several decades has produced a range of psychometrically validated measures.

The My AT Outcomes Framework (MyATOF) offers an alternative 'starting point' that provides AT users and stakeholders access to a co-designed, evidence-based, and holistic set of outcome dimensions.

MyATOF was devised to capture the AT user's perspective across relevant dimensions and comprises a series of questions that summarize information about the AT user's needs, goals, and context. Data are captured in the areas of

MyATOF dimension	Operational framework and supporting literature
My Supports	Assistive products and environmental adaptations subset, drawn from current edition of ISO 9999 (ISO, 2022) and the local AT database in each jurisdiction for example [how to reference NED and /or EASTIN]
My Outcomes	WHO ICF Activity and Participation domains (World Health Organisation, 2001, 2018)
My Costs	Aspects of cost (direct costs, indirect costs, social return on investment) based on economic pathway analysis from a sector perspective (Carter et al., 2008; Layton, 2014; Layton et al., 2020; Layton & Irlam, 2018; Layton & Shih, 2018)
My Rights	Subset of 12 Articles from United Nations Convention on the Rights of Persons with Disabilities (United Nations, 2006; Watchorn & Layton, 2011). Noting the articles selected explicitly call up AT, however many more articles are in scope if deemed relevant to users of MyATOF
My Service Delivery	6 AT service delivery steps (de Witte et al., 2018; Fagerberg, 2011; WHO & UNICEF, 2022; World Health Organisation, 2020)
My Customer Experience	8 aspects of customer experience (De Jonge et al., 2015; Dijcks et al., 2006; Larsson Ranada & Lidström, 2019)

Table 1: Operationalization of the six dimensions comprising the framework

(a) supports, (b) valued outcomes, (c) costs and cost offsets, (d) human rights, (e) service delivery pathway, and (f) customer experience. Table 1 on previous page outlines the operationalization of the six dimensions comprising the framework.

Data are summarized into report formats, enabling the AT user to inform practitioners and funders regarding a need for specific AT. The data fields are benchmarked against international standards and available evidence.

Study aims

MyATOF had not yet been used with people with deafblindness or outside of Australia, and the aims of this study were to:

a. determine the relevance and face validity of MyATOF for use with people with deafblindness in the SADC
b. refine the tool, if relevant and valid, to increase its relevance and validity in this context
c. deepen the understanding of the context of AT provision and use by people with deafblindness in the SADC.

Study design

Delphi methodology was chosen for this study as the purpose of this approach is to achieve consensus or priorities among an expert panel on a certain topic, where agreement was not previously determined. In this study, two rounds of electronic surveys using the Qualtrics Platform (www.qualtrics.com) were completed. Participants unable to access the electronic survey had the option of being emailed an MS Word version of the survey. A pilot (n=2) was conducted during Phase 1 of the survey to confirm accessibility.

Study population

A heterogeneous e-Delphi expert panel, representing the diverse stakeholder group across the field of deafblindness in the SADC was selected. The criteria of eligibility to participate in the study were:

– people with deafblindness over 18 years old
– family members of people with deafblindness
– educators with a minimum of three years' experience working in deafblindness
– researchers with a minimum of three years' experience working in the field of deafblindness
– service providers with a minimum of three years' experience working in the field of deafblindness
– representatives from advocacy groups who had a minimum of three years' experience in working with people with deafblindness.

Purposive and snowball sampling were undertaken to develop a list of potential participants for the Delphi expert%panel. Seventeen participants (representing four countries) responded and completed Delphi Phase 1. Of%the 17 participants who completed Phase 1, 15 completed Phase 2 (representing four countries).

Data collection

Participants were asked to look at all MyATOF dimensions and state whether they perceived them to be (a) relevant to people with deafblindness, and (b) relevant to the SADC context. Participants were invited to provide additional comments about each section of the framework. Participants were anonymous to each other and the researchers, giving equal opportunity and weighting to the ideas of each panel member.

Data analysis

Both quantitative and qualitative analyses were undertaken with the data from each Delphi round. An initial, thematic analysis of the qualitative responses was conducted. The themes arising from the initial analysis of comments made by participants in response to the questions in Phase 1 were reviewed by all authors. Consistency between the themes emerging from the data and the WHO 5Ps was identified. An analysis of the qualitative data, using the existing themes from Phase 1 was undertaken with the Phase 2 data and existing sub-themes were expanded or new sub-themes added, if the existing themes did not adequately capture new ideas emerging from the Phase 2 data. Some further modifications were made until consensus was reached by all three authors.

Results

Considerable consistency was observed in both phases, apart from two sub-themes in the second phase. From the qualitative data, key issues were identified to be addressed regarding AT provision to people with deafblindness in the SADC region.

Phase 1 results

Overwhelmingly, 100% of the 17 participants in the Delphi panel, agreed that the set of questions in each section of MyATOF were relevant both to people with deafblindness and the SADC context.

A summary of the qualitative data for each tool of the MyATOF is presented below.

Tool A – My supports: What AT and other things do I use?

In their responses, the panellists described the use of AT as enabling the achievement of outcomes, and endorsed and expanded the sub-set of products suggested for deafblindness.

Tool B – My outcomes: What does my AT enable me to do?

Panellists endorsed the broad spectrum presented and raised some issues specific to people with deafblindness and SADC context.

Tool C – My costs: How much does my AT cost? How much does my AT save?

Panellists identified costs as a major barrier

Tool D – My rights: How does AT meet a person's human rights?

Panellists described a lack of realization of rights.

Tool E – The AT Service Delivery Pathway

Panellists endorsed the notion of a service delivery process.

Panellists said they wanted:

– the best combination of devices, personal care, and environmental design
– access to sufficient funding for good quality and long-lasting devices

See below 5Ps and sub-themes deduced from analysis of the phase one qualitative data.

1 People

a. Raise awareness of deafblind people about social inclusion
b. Raise awareness of deafblind people about their human rights
c. With the right assistive products and services, people with deafblindness can become employed
d. There is a need to develop the assistive-technology-related skills of family members

2 Policy

a. Government must implement the CRPD [Convention on the Rights of Persons with Disabilities] (human rights conventions)
b. Policy should support deafblind persons by paying for AT
c. Deafblind persons should contribute to the cost of their AT
d. Governments should make AT available that is relevant to people with deafblindness

3 Products

a. AT products are not available because they are not affordable for most people with deafblindness
b. AT products are not available because they are not produced in African countries
c. AT products are not available because they are imported and there are big costs with import duty and foreign exchange
d. Physical environments are not adaptable or accessible. The interface between AT and environments must be considered

4 Provision

a. There is limited availability of AT products or services to people with deafblindness in my experience
b. Governments need to play more of a role in AT provision
c. It is helpful to know where to go for advice and for products
d. Empower deafblind people with assistive technology as it is cost effective compared to human supports

5 Personnel

a. There is a need for staff awareness and skills development about deafblindness, in general health and disability services
b. There is a need for staff awareness and skill development about deafblindness, in all areas of government and social services
c. It is important to provide training (AT services) as well as AT products
d. It would be useful to have a training package about deafblindness and AT

- funding to meet AT needs in every area of life, based on a holistic assessment of needs, so that each product works well and does not interfere with other supports
- consideration of AT needs across people's lifespans and as needs change
- support throughout the process of obtaining AT, including product trial, training, and maintenance
- access to resources when needed
- active involvement in decision-making
- consideration of personal preferences and identity so that AT is chosen to suit lifestyle and participation.

Phase 2 results

In the Phase 2 survey, panel members were invited to identify the level of importance that each of the 20 sub-themes, derived from the Phase 1 data, held for addressing the assistive technology needs of people with deafblindness in the SADC region.

Six of the twenty sub-themes were viewed as being very important by all members of the Delphi panel:

- Raise awareness of deafblind people about social inclusion
- Government must implement the CRPD
- Governments should make AT that is relevant to people with deafblindness available
- Governments need to play more of a role in AT provision
- There is a need for staff awareness about deafblindness and skills development in general health and disability services
- There is a need for staff awareness about deafblindness and skills development in all areas of government and social services.

Most of the sub-themes were viewed as being very important by more than two-thirds of the Delphi panel, with the remaining members viewing them as quite important.

Only the following two sub-themes were viewed as being not important by some members of the Delphi panel:

- Deafblind persons should contribute to the cost of their AT (five participants indicated "not important").
- AT products are not available because they are not produced in African countries (one participant indicated "not important").

Theme 1: people

Panellists identified the key role of stakeholders, their awareness, knowledge, and exposure, in realizing the potential of using assistive products to achieve the quality of life, productivity, access to opportunities, and enabling people to "follow our dreams to fulfil our passion and enrich others' lives".

Theme 2: policy

Policy was regarded as being a highly relevant aspect of access to AT, with panellists identifying the impact of policies upon costs and financial access.

Theme 3: products

Broad agreement was evident across themes, with panellists noting that AT products play a critical role.

Theme 4: provision

Panellists were consistent with original themes and with the WHO.

Theme 5: personnel

A very high level of concurrence with the themes was noted. The panellists provided a clear picture of the pivotal role of personnel in enabling AT access and use.

Conclusion

While contexts differ, AT users globally, including those with deafblindness, share common, unifying human experiences and aspirations. Using the MyATOF, these are supports, outcomes, costs, rights, service delivery steps, and customer experiences. The results of the Delphi process undertaken with deafblind stakeholders across four countries in the SADC region support the face validity of the framework dimensions. Analysis of the data suggests that the experience of accessing AT and achieving participation outcomes is extremely challenging, and the evidence generated could be clearly mapped onto an AT systems view based on the WHO 5 Ps model. The achievement of individual outcomes must be viewed in the context of systemic barriers. It appears that tools such as those offered by MyATOF have the potential to enable the collection of individualized data and self-advocacy and to contribute to the systemic advocacy necessary for the realization of rights.

Full details of the study are free to download here:
The study was supported with financial support from Deafblind International. For information about the Deafblind International African Researchers' Initiative see: www.deafblindinternational.org/african-researchers-initiative-1st-african-dbi-conference/



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UCL

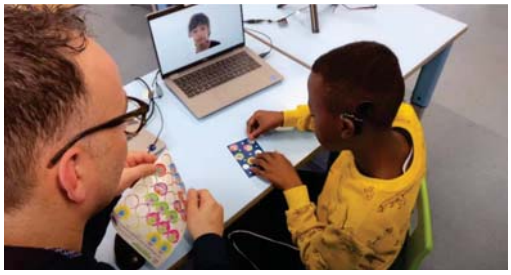
Visual Communication and Reading Development project – University College London

Visual spoken language input (visual speech/ lipreading) is increasingly being recognised as important to language development and reading development not only in deaf children, but also in hearing children. The importance of sign language knowledge to reading development in deaf children is also well established.

In our research project we aim to examine the contribution of visual speech and also sign language to reading development in deaf children over 3 years from Reception to Yr 2. We have already recruited children who joined Reception in 2022.

Could you help us recruit more children by sharing information about the project with parents of deaf children at your school?
We are recruiting deaf children who:

- will start Reception in September 2023 or 2024 (approx. 4yrs old)
- were diagnosed as severely or profoundly deaf before 3yrs old
- have lived in the UK for at least the last 6 months
- have no disabilities that would prevent them from completing 10-15mins of tasks on a computer



For further information please visit:

https://www.ucl.ac.uk/icn/research/research-groups/visual-communication/visual-communication-reading-development-project **which you can also access by scanning the QR code below.**

Or email us at - visualcr@ucl.ac.uk

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